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Uncivil society: the politics of HIV activism in Pakistan

Abstract

This paper presents ethnography of the ‘Association of the People Living with HIV’ in Pakistan, established under the auspices of UNAIDS, international NGOs and the government’s AIDS control department as an attempt to strengthen ‘civil society’. It was initially run by formerly marginalised HIV positive leaders of Community Based Organisations (CBOs), until a university-educated America-returned young HIV activist was selected as its national coordinator. One of the ways in which this new entrant undermined the dominance of long-established leaders of the ‘PLHIV (People Living with HIV) sector’ was to democratise the Association by attempting to hold country-wide elections among HIV positive people and de-linking the Association from the CBOs. The resulting tug of war between the pioneers of HIV activism and a privileged newcomer with a savvy agenda revealed politics of community, the importance of numbers, the ideal of democracy and breaking down monopolies. This paper explores how the Association became a site of contested claims instead of serving its envisaged purpose of bringing HIV positive people on a common platform and agenda for shared good. I argue that the recent literature that examines the activism of HIV positive peoples in terms of ‘biological citizenship’, or their organisations as spaces where people are subjectivated as ‘therapeutic citizens’ with a potential for worldwide solidarity, must be reconsidered in light of the local histories and sociologies of HIV, and for an appreciation of the moral complexity of the activists.

Introduction

“The only thing they really share is that they are all HIV positive. They don’t share a real social commonality...These people are men, women, from different classes, and different backgrounds”

(UNAIDS country coordinator for Pakistan)

It has been argued that the emergence of ‘AIDS exceptionalism’ (Smith and Whiteside 2010) has allowed for a ‘government-by-exception’, which requires “the enrolment, or calling-into-being, of specific exceptional populations to be saved by foreign agents”, in sites that are not bounded geographically but “exist both within and without a national border” (Nguyen 2009: 212). Biological and political technologies are applied to transform people into ‘PLHIV’ through targeted interventions, mass treatment, community building, empowerment, and participation programmes. As they struggle to gain access to antiretroviral medicines (ARVs) through right-to-health litigation (Biehl 2005; 2007; Biehl and Petryna 2011), and as they wage a politics of shame and passion against governments and ‘Big Pharma’ (Robins 2006), the political organisation of PLHIV, it is argued, has become a space where HIV positive people are subjectivated in ways which “herald a novel form of political power: *therapeutic sovereignty*” (Nguyen 2010: 6). This transformation into ‘therapeutic citizens’ is seen

optimistically as an opportunity where these ‘exceptional people’ would “wrest control over their destinies and foster a new solidarity” (Nguyen 2010: 184) on the basis of their shared HIV positive status.

The term ‘biological citizenship’ was first used by Adriana Petryna (2002) to describe social practices in Ukraine whereby impoverished citizen-victims of the Chernobyl disaster mobilised around their claims of radiation-induced injuries. According to a recent characterisation of the concept by Rabinow and Rose (2006: 202), biological citizenship emerges when “patients’ groups and individuals increasingly define their *citizenship* in terms of their rights (and obligations) to life, health and cure” (see *inter alia* Liguori and Lamas 2003; Biehl 2007; Rose and Novas 2008). The hopeful claims of anthropologists around the emergence of ‘biosociality’ (Rabinow 1992), biological citizenship and new forms of solidarity among HIV positive people have received the highest level of financial endorsement by UNAIDS, the Joint UN Programme on HIV/AIDS, which has committed formally to the ‘Greater Involvement of People living with AIDS’ – the ‘GIPA Principle’ (UNAIDS 1999). Against an emphasis on ‘rights-based approaches’ (Parker 1996) in international health and development, the governmentality of the GIPA Principle seeks to foster a political force for empowerment and countering the stigma and lack of dignity of HIV positive people. There are resonances here with the wider commitment to ‘civil society’ as harbinger of democratization, that “melange of associations, clubs, guilds, syndicates, federations, unions, parties and groups [who] come together to provide a buffer between state and citizen... [whose function] is literally and plainly at the heart of participant political systems” (Norton 1995: 7; cf. Lewis 2004).

In this paper, I argue that claims about the activism of HIV positive people in terms of biological citizenship, and about their organisations as spaces of subjectivation as therapeutic citizens with a potential for worldwide solidarity, need to be reconsidered. The moral complexity of the activists, as historically situated individuals, must be taken into account. I discuss ethnography of an ‘Association of People Living with HIV’ in Pakistan (henceforth, the Association) which shows that instead of strengthening civil society, GIPA-driven HIV activism reveals many of the ‘uncivil’ facets of society. Despite the UNAIDS’ political technologies of community building, democratising participation, strengthening civil society and so on, the biological condition of HIV activists in Pakistan was not so much a fount of sociality as were the distinctions of class, religion, education and gender among them, which they pressed into the service of their claims to leadership. The donor funding for the Association made it into a site of conflict and competition instead of serving its envisaged purpose of bringing HIV positive people on a common platform and agenda. These observations require us to prise open the HIV activists’ multifaceted and situated moralities rather than reducing them, in our analyses, to ‘therapeutic citizens’ and anticipating solidarity on the basis of shared HIV status. In the rest of this introduction, I will review some of the literature that helps to bring out the limitations of a biopolitical approach to activism, followed by contextualising this paper in the anthropology of Pakistan, a description of HIV prevalence in the country and my fieldwork. The main body of the paper builds on ethnography and life histories of HIV activists in Pakistan.

Like many other ‘travelling rationalities’ (Mosse 2011) in international health and development, the idea of the Association was transplanted in Pakistan in 2008 in the hope of empowering HIV positive people in accordance

with the GIPA. However, as suggested by the quote with which I began this paper, even the UNAIDS country coordinator was gloomy about the prospect that the Association would create a common platform and effect political change. His comments join a growing body of scholarly criticism of concepts such as biological citizenship and biosociality, suggesting that such optimism may need to be revisited in the light of the “complicated local histories and sociologies of disease” that Jean Comaroff has argued “are obscured by grand allegories of exclusion, crisis and apocalypse” (2007: 209). Comaroff provides an initial touchstone for a critique of biological citizenship by arguing through southern African ethnographies that the framing of HIV positive people must move beyond treating them as ‘bare life’ (Agamben 1998). Such reductionist framings tend to reduce all politics to biopolitics, people to bodies, and life merely to bare life – *zoe*. They do not take into account that the successful movements for the rights of HIV positive people have occurred in the contexts of strong tradition of activism around health and other issues. For example, Steven Epstein (1998:12) has documented how the AIDS movement in the United States was built on the foundations of other social movements, in particular the lesbian and gay movements of 1970s and 80s. Schneider (2002), Robins (2006), Fassin (2007), Kielmann and Cataldo (2010), and Mbali (2013) have argued similarly that South African AIDS activism builds on anti-apartheid and trade union mobilisation in the country. More fundamentally, as Didier Fassin (2009: 48) has reminded us in his critique of Rose’s molecular vision of a political order governing ‘life itself’, life is lived through both a body and a society, and it has meanings and values attached to it.

In the south Asian context, Aditya Bharadwaj (2008:109-111) has shown that in IVF clinics in India, patients are not assembling so much around their biological condition, with a view of actively carving out a sociality, as they were made ‘bioavailable’ in a market of anatomical extraction and insertion, driven by neoliberalism and fuelled by patriarchal expectations of reproduction. He argues that whilst some form of biosociality may emerge among devotee patients around the messianic figure of an IVF/stem cell clinician, “the social trajectory of the bio and its biographical inscription seldom produce individual or group identities”. This reads quite unlike the PLHIV identity that has been promoted for HIV positive people to emerge as a political force.

A series of ethnographies of HIV positive people from sub-Saharan Africa have delimited the boundaries of this new biopolitics. Beckmann and Bujra (2010) show that organizations of HIV positive people may not always become a political force to be reckoned with. In Tanzania, they stick to marshalling people for treatment and service delivery – a ‘politics of the queue’ rather than biological citizenship. Boesten (2011: 785) shows that to obtain the rations of food and medication that they need to survive, ‘poor and positive’ people in Tanzania must navigate a disjointed landscape of competing, unsustainable donor-dependent agencies which “undermines, rather than strengthens political action and voice”. Marsland’s (2012) HIV positive informants do not choose to associate on the basis of their biological condition, but on the basis of pre-existing relationships of family, friends and neighbours. Similarly, Prince (2012) notes that HIV positive people in Kenya talk more about their ‘needs’ rather than ‘rights’, and that these needs are not articulated as a political force to challenge the state, but deflected through a rapacious NGO economy. Most recently, Whyte and colleagues (2013:164) have advanced the concept of ‘therapeutic clientship’, as opposed to ‘citizenship’, to account for the relations among HIV positive people in

Uganda, who “are not so much claiming rights, as hoping for help from a ‘patron’ with resources to distribute”. These interventions indicate that there is a moral economy to the HIV positive organizations that have developed in countries like these, where HIV activism intersects with international aid regimes, and ironically, that the financial endorsements extended by international donors may fragment the political force they hope to foster.

My material requires me to push the argument further and open up the complicated moralities that animate HIV activists in Pakistan, in line with recent work in the anthropology of morality that has highlighted the multiplicity and situational nature of moral subjectivities. Howell (2005), Zigon (2008; 2010) and Mattingly (2012) have explored the complexity of moral subjectivities by examining processes of moral reasoning and reflexivity, demonstrating that individual moralities are highly contradictory. This is useful for understanding the HIV activists in Pakistan, who emerge from lives turned upside down by sickness and stigma as entrepreneurs and patrons, capable of both generosity and exploitation. I suggest that this has implications for the recent suite of anthropological studies, which have depicted activists as forced by the struggle for survival to navigate the exigencies of the AIDS industry, but stopped short of apprehending their accumulative and political strategies. The biopolitical literature frames HIV activists either as heroes, emerging political actors on the local and transnational stage, whose lives and identity revolve around their HIV infection; or as victims, subjects of a transnational therapeutic sovereignty. In any case, both approaches restrict a full appreciation of their lives and politics. Moreover, acknowledging the moral complexity and ambiguous moral choices of the HIV activists has implications for the dominant models of HIV intervention, which have valorised the participation of PLHIV, as if HIV infection turns a heterogeneous mass of people into a single body - a community of need with a singular concern to survive and a singular morality of helping other HIV positive people to survive.

As the broader societal developments are worked into HIV activism in various ways, the ethnography presented here finds many resonances with recent anthropological research in Pakistan. The Islamicisation of the Pakistani polity, Islamic ethical life and everyday lived Islam have been stressed (see the collection of articles in Marsden 2010). This has significant implications for HIV activism, as HIV/AIDS is still constructed in the national media and popular discourse as disease of foreigners, sexual perverts and ‘dirty’ drug users. The relations of patron-client, which have been much-discussed and even suggested to be ‘foundational’ to Pakistani society (Lyon 2004), are also pervasive in the field of AIDS activism. However, patron-clientism in the HIV sector takes us outside the existing descriptions of voting patterns and *thana-katchari ka kaam* (intervention in police stations and courts) as mediated by *biraderi* (clan) factionalism (Chaudhary 1999; Nelson 2011), relations between landlords and tenants, *peers* (saints) and their followers (Martin 2009) – and into the heterogeneous terrain of international NGOs, state bureaucrats and ‘civil society’. Recent literature has explored the materiality of the state bureaucracy, its proceduralistic reliance on files and paperwork in the mould of the colonial *kaghazi raj* (paper government) (Hull 2012) and the corruption of the voluntaristic nature of Pakistani civil society by its on-and-off funding by international NGO donors (Bano 2008). This paper, however, extends the remit of this debate

to the subjects of interventions by NGOs, donors and the state bureaucracy in the HIV sector. It explores the organisation of HIV activism and the bureaucratic interventions that aim to infuse biosociality among them.

Pakistan has historically been a country of low HIV prevalence, but has gradually moved to the stage of a ‘concentrated epidemic’, classified by international agencies as at high risk of ‘generalised HIV infections’ (UNAIDS 2013). With an estimated seroprevalence of 0.1%, 130,000 people are estimated to be HIV positive, yet less than 6000 are registered with the government Antiretroviral Therapy (ART) centres (NACP 2012; UNAIDS 2013). In this ‘epidemic of signification’ (Treichler 1987), the dominant epidemiological discourse on HIV in Pakistan has borrowed substantially from studies from Africa and South East Asia, which “set a precedent for research in nearly all ‘Third World’ countries, where prostitutes and truck drivers would become the focus” (Karnik 2001: 341). This ‘global foreknowledge’ (Mahajan 2008) of the epidemic has resulted in a programmatic focus on male and female commercial sex workers, injecting drug users, *hijray* (transgendered people), and ‘men who have sex with men’ (MSM) with the financial assistance of external donors like the World Bank and the Global Fund for AIDS, TB, and Malaria (NACP 2007).

In 2010-11, I worked as an intern at Pakistan’s AIDS Control Programme (ACP) as part of my doctoral fieldwork on the biopolitics of HIV in Pakistan, a multi-sited organizational ethnography (Marcus 1995; Gellner and Hirsch 2001; Hastings 2013). This paper draws from that fieldwork. I took part in the everyday life of the section of the ACP in which I worked, participating in meetings with donors and NGOs, seminars, conferences, trainings and dissemination events, drafting correspondence and reports that were passed between colleagues. I maintained daily fieldnotes. In addition, I carried out more than two hundred interviews with key individuals in the HIV sector as well as ‘high risk’ populations, as designated by the ACP (see [reference removed for anonymisation]). These included current and former office bearers of the Association, CBO leaders, ACP and UNAIDS and other donor officials and HIV positive individuals.

In the following I begin with the life histories of the pioneer HIV activists in Pakistan, and then move to discuss the contestations that were taking place over the Association during my fieldwork. By the time the Association was set up in 2008 there were more than 4000 registered HIV positive people at the government’s ART centres. The Association was initially run by CBO leaders who came from poor and marginalised backgrounds. However, this was challenged when a university-educated, US-returned, young HIV positive man was selected as its national coordinator. One of the ways in which this new entrant undermined the dominance of long-established leaders was to democratise the Association by holding elections of the executive board and delinking it from the CBOs. However, this move was controversial, further fragmenting the HIV activists over issues of community, numbers, democratic ideals and the monopolistic control of HIV activism in Pakistan.

Pioneering HIV activism

The history of HIV activism in Pakistan began with Franciscan Brother Munshi Masihⁱ at a Catholic church in Lahore, who was sent by the church to the Philippines on a training programme in 1993. For the first time in his life he met with AIDS patients and heard their stories. He was so moved that upon his return he set up the ‘AIDS Society’, bringing together four HIV positive men and their families, who were all Christian and belonged to a lower socio-economic class. One of them was Bashir. The four families would meet fortnightly in a private house to share their common experiences of suffering (*dukh sukh*) with each other. “AIDS was considered as a disease of non-Muslims. We were worried that we might be targeted by extremists”, recalled Bashir. He had worked as a migrant labourer in the Gulf from 1977 to 1990, during which he got married among his relatives back in Pakistan. In 1990, he was required to undergo a medical examination as part of new regulations for visa renewal. Before he could be tested officially, he got his tests done privately and discovered that he was HIV positive. In order to avoid the humiliation of deportation on the basis of his HIV status, he voluntarily returned to Pakistan where he went again for HIV testing in one of the most expensive laboratories in the country. To his surprise, he was tested negative. Doctors gave treatment for sexually transmitted diseases for months before he was finally confirmed HIV positive in 1991, at a time when most people in the health establishment had not yet come face to face with this condition. Inconsistency in HIV testing is still a problem for prospective Gulf migrants in Pakistan ([reference removed for anonymisation]).

The government’s health officials gave him a plastic-coated HIV positive identity card to wear around his neck, thinking that he might die anytime, anywhere, and that whoever were to touch the corpse should do it carefully after reading the instructions on the card and inform the officials on the given phone numbers. The health official forcibly tested his family members for HIV. Some newspaper reporters, posing as government officials, tricked them into being photographed for official purposes. The next day, these photographs appeared on the front pages of local newspapers with captions like ‘Pakistan’s first AIDS patient’ - turning Bashir into the face of an alien disease of immorality. After hiding for some time in his house, during which the family survived on his savings from the Gulf, he finally came out and set up a bicycle repair shop, deploying a skill he had learnt as a child.

For five years they lived in extreme poverty and social ostracisation. They could no longer support their children’s education or afford new clothes for them. His brothers distanced themselves from him, his wife and children. A neighbour tried to force him to shut down his bicycle repair shop and move out of the locality. On the other hand, the group of four HIV affected families that had provided them some consolation started to fall apart with the death of two members from AIDS – at that time there were no ARVs available and they were so poor that they could not even afford common medicine for ordinary infections and illnesses. “If we had medicine, our diet was not good. If we had food to live on, no doctor would want to touch us when we fell sick”, recalled Bashir. Of any support he received during this turmoil, he counted the most on his wife’s prayers and fasting for him, which, he believed, gave him strength.

He braved these early experiences of diagnosis and medicalisation of his being with extreme hardship and without any support from the government or the 'civil society'. In the meanwhile, a major development was taking place at the international stage which would have far-reaching impact on his life. In 1996, UNAIDS was established with an agenda of coordinating HIV response of all UN agencies and advancing a 'rights-based approach' which would prioritise the greater involvement of people living with AIDS – the GIPA Principle. In Pakistan, they picked Bashir as the representative of PLHIV because he was the most known among HIV positive people due to the number of news stories about him carried in local papers. They sent him to international conferences and workshops, invited him to their meetings, and introduced him as an important policy stakeholder to the government's AIDS bureaucracy. Such involvement in high level forums has often been seen as 'AIDS tokenism' (NAPWA 2004), but for those like Bashir who suffered from extreme stigma and discrimination, it represented 'making the best out of the bad situation' and 'living positively with AIDS' (Kelly 1998:210).

By religious background, Bashir was a Christian in an Islamic state-society where the popular perception was that AIDS was a disease of non-Muslims. He was also unemployed and on the brink of destitution, a sole provider of a family of large number of dependents which included five young children, a wife and elderly parents. Socially, he already belonged to the underprivileged and was pushed further to the margins. Nevertheless, this 'multitude of oppressions' (Hamar 1996) would now have a different meaning and use for him. With some encouragement from UNAIDS, Bashir became the first Pakistani to publically declare himself HIV positive. The newspapers and TV channels, which had brought shame and stigma to him and his family by breaking his story a few years ago, were now partners in his activism. He said he felt a particular affinity with international donors and expatriate workers who were seen as 'fellow Christians'. On one occasion, he successfully invited the American ambassador to visit his CBO in the bicycle repair shop and extend support to it. Bashir quickly learned to use his narrative of suffering to creatively make use of the resources he had to hand.

In 1999, he founded the first CBO of HIV positive people in Pakistan, Shining Star. Sponsored by an international (Christian) faith-based NGO, their first task was to register HIV positive people for food rations, school fees and common medicine. Bashir and his peers spent hours outside ART centres, hospitals, laboratories and private clinics in order to convince the newly diagnosed HIV positive people of the benefits of registering with Shining Star. They built extensive networks of information exchange with staff of health facilities to obtain the names and addresses of the newly diagnosed, and followed them to their homes to help them come out and register with them. Sometimes, it would take them months to convince an individual and/or his family because of the stigma around talking about HIV/AIDS. "I could understand their fears because I had myself gone through all that", said Bashir, but he hardly ever gave up on them.

In 2003 Bashir's health deteriorated so much that he said, "I thought I was not going to see the year 2004. For twelve years we never imagined that the ARVs would ever be available or our lives would be saved". Around this time, the country representative of his donor organisation (faith-based international NGO) visited Shining Star's office in the bicycle repair shop in Lahore. According to Bashir, the NGO boss was so moved by his personal

suffering and ambition that he sent one of his men to India to bring six months supply of ARVs for Bashir and the three other core members of Shining Star. Encouraged by this, Shining Star started a fund raising campaign to procure these life-saving medicines for a number of their CBO members. Between 2003 and 2005, they claimed to have provided free-of-cost ARVs to at least 37 individuals. In raising these funds, Bashir used his unique position as an HIV positive Christian in the Islamic republic, who was the first to ‘come out’ publically to work for those suffering with a disease whose very existence was denied in the country. From a disease of foreigners, non-Muslims, and non-Pakistanis, AIDS had gradually moved to be conceived as an affliction upon the denigrated groups of prostitutes, *hijray*, homosexuals, drug users and *churhe* (a derogatory term for Christians/sweepers) involved in sexually licentious activities (see Pigg 2002).

Gharailo aurat (home-maker) turned activist

“Bashir will never tell you this”, said Kiran, “but I was the one who set up Shining Star, not him!”. In her version of the story, Kiran and Bashir were taken to a district hospital for an HIV awareness session in 1998. Their role was to embody HIV and share their experiences with nurses, doctors and paramedics – but only within the parameters defined by their ‘handlers’ who had arranged the event. Kiran decided that these HIV experts were using them only as ‘tokens’ to make money from international donors. She had this thought for quite some time, as she said; “I was like a piece of white paper (*kora kaghaz*) on which other people had started writing. It’s very painful to have someone writing on you”. That day she decided to take the reins of her life in her own hands. “What they do is nothing that we can’t”, she told Bashir; “if it’s us who are required to speak in these sessions, why then, should someone else put words in our mouth and take away all the money?”. This was how she claimed she was the one who started Shining Star. In any case, she parted ways with Bashir and went on to set up her own CBO called Live Positive in 2003. At the time of my fieldwork in 2011, she was a middle-aged, single parent of a teenage son and a daughter living in a comfortable house in a middle-class locality of Lahore. Chandeliers, matching china dinner sets and kitchen appliances were the accoutrements of her newfound comfort.

In 1995, her husband was hospitalised for multiple illnesses. He was diagnosed with HIV. The medics shifted him from the medical ward to a ‘store room’ and asked Kiran to bring herself and her children for blood tests. She tested positive. On the next day, the hospital sources informed the media about their ‘discovery’. The husband died within a week and his family burnt everything that had come in contact with him. Thankfully, they spared Kiran and her children. She was put under immense pressure to leave her husband’s house. Since then, she promised herself that she would learn as much as she could about this disease and why it was so dangerous. She said, although she had twelve years of schooling, she had always remained a *gharailo aurat* with little knowledge of words like ‘prevention’, ‘transmission’ and so on. “If you bring a *gharailo aurat* out in the open and ask her to run, she won’t know where to go. That’s what happened to me as well. I was a typical housewife. I didn’t know which path led where, what to do and how to do it”, she said.

One of the paths she took led her to the ACP where a friend of her nephew worked in a clerical position. Here she was introduced to a group of HIV positive people led by Bashir who, according to her, had brought them together mainly on the basis of religious (Christian) solidarity. She joined the group as the first Muslim, first woman, and the first educated person. She therefore had an edge over others, she claimed, as she could 'pick' things more quickly and imbued confidence in the rest of them to work as a 'community'. This was the beginning of Shining Star, as she claimed. However, mingling with unrelated men in this group did not go well with her conservative relatives. She had to distance herself from the nascent HIV activism and part ways with Shining Star. Instead, she took up stitching and embroidery to earn a living. She was rediscovered in 2001 by some officials of a provincial AIDS control programme and the boss of an HIV awareness NGO, who convinced her to come back to the field of activism. "I told them very clearly that I had some earnings to run my family and if I joined this sector again, I would be doing so by sacrificing my extended family's support", she recalled. The 'Karachi people', as she called them after the name of the biggest city in that province, agreed to take care of her financial needs. They helped her become the PLHIV representative in the CCM (Country Coordination Mechanism for the Global Fund for TB, HIV and Malaria; an influential position in the HIV sector). Her opponents criticised her for working as a stooge for the 'Karachi people', to watch their interests in the CCM and to counter Bashir's influence as the PLHIV leader with closer ties to a different provincial AIDS control programme.

When Kiran set up Live Positive in 2003, Shining Star had a competitor for the membership of HIV positive people for the first time. Both CBOs were driven by the personalities of their bosses. Bashir was the original, authentic, embodiment of HIV suffering in Pakistan. Kiran was a widow, an innocent victim, thrown out of marital family, a *ghrailo aurat* turned into an activist. By 2005, she had come a long way, measured her strengths and mapped the territory. She took a very big step; something which she said "could make or break my life". She did not tell her family about it because she knew if she did they would never approve of it. She also knew that if it went wrong, her children's future will be in danger. But again, she was encouraged by the same Karachi people to become the 'first drop to make an ocean', to be an example for others. Astonishingly, a documentary on her life and work was aired on CNN on World AIDS Day. This big step for Kiran coincided with an international conference on women's health and rights, to which she was also invited. Some UN regional officials participating in this conference saw the documentary that morning. In the opening session of the conference, the UN officials called Kiran on the stage and gave her a resounding appreciation for her courage and bravery, "for openly disclosing my HIV status in front of the whole world". She recalled with excitement;

It was like a bomb had exploded. The media personnel covering the conference did not yet know about my documentary. They all converged on me to speak to me about it. Even the conference organisers were worried that I was stealing their show... That evening, there was not a single TV channel that did not carry my interview.

It was a successful performance by all means. Now Bashir had a competitor in the field of HIV activism. Many years ago, he had given a similar 'performance' at a Memorandum of Understanding signing ceremony between the government and UNAIDS in Islamabad, when he declared himself as the first HIV positive person to

voluntarily ‘come out’ in front of cameras. Kiran had now done the same, but on a grander scale, by running a documentary on CNN and following it up with a spectacle at the women’s conference on World AIDS Day. Distinctively, she was the first HIV positive woman – a *gharailo aurat*, an ‘innocent victim’ (see Pigg 2002 on the politically palatable category of ‘unsuspecting wives’ in south Asian epidemiology) – to ‘come out’ in Pakistan. Nevertheless, as time passed, the narratives of suffering – that is, of ‘victims’ transformed into ‘survivors’ (Diedrich 2007) – were not enough in the scramble for funds for both these proprietors of CBOs. Lawrence Cohen (2005:271) has described the politics of competing interests and ideologies in the Indian HIV/AIDS sector as ‘AIDS cosmopolitanism’; ‘an imagined formation of dislocated agents using the economically fortified social enterprise of AIDS prevention to support its own covert projects’. To transform themselves, yet again, as ‘thrivers’ in the field of HIV activism, Bashir and Kiran had to show numbers in addition to embodying sufferings, championing a PLHIV ‘community’ and allegiance to ‘civil society’.

Acknowledged competitors over the membership of HIV positive people with their respective CBOs, Bashir and Kiran had, nonetheless, similar personal stories of pain. Coming from underprivileged backgrounds, they often stuck together in the midst of western-educated English-speaking pundits of HIV sector in donor organisations, government and the ‘civil society’. These two had more in common with each other than either of them had with those westernised elite, and more in common than the HIV virus alone – a multitude of affinities. For example, on one occasion, in a high level meeting when the donors and government officials discussed modifying the care and support package for HIV positive people to include a greater focus on improving their livelihoods via socioeconomic support and job creation instead of simply providing food, medicine and cash support, I saw Bashir echoing Kiran’s strong objection. While Kiran asked the participants emphatically “what if they [the PLHIV] die of hunger?”, Bashir observed that people like him, who belonged to an earlier crop of PLHIV and had benefited from a better nutritional support programme, had longer life expectancy by comparison to those who were diagnosed later when such programmes had become less effective.

The unavailability of ARVs in Pakistan was another issue around which these two CBOs gathered momentum. In this age of ‘pharmaceutical salvation’ (Kistner 2003; Biehl 2005), ARVs were not yet available in the government sector in Pakistan by 2005, although unlike South Africa under President Mbeki (see Schneider 2002; Robins 2006; Fassin 2007), there was no ideological resistance by the state towards the provision of ARVs. The CBOs successfully lobbied for free-of-cost availability of these medicine in the country by ‘marshalling’ (Beckmann and Bujra 2010) their members to World AIDS Day events to show their presence *en masse* and share their stories of suffering. They called upon the donors and the government to start HIV treatment programmes. After the ART centres were established in major cities, the CBOs worked as ‘organisational conduits to assist ARV provision’ (Lyttleton, Beesey et al. 2007: S49) by lining their members up for treatment. They kept their records, followed them up in their homes to bring them back after initial visits, and delivered donor-sponsored ‘care and support’ – turning them into ‘dysfunctional patients’ of chronic illness, if not ‘responsibilised citizens’ of a welfare system (Robins 2005: 22). However, when the government and UNAIDS

drafted a 'National HIV-AIDS Law' to facilitate the legal protection of outreach workers carrying out HIV prevention among quasi-legal groups of sex workers, MSM and *hijrae* – under the Pakistan Penal Code, extramarital sex is an offence against the State, liable to death by stoning in some cases (Jahangir and Jilani 1990) – the CBOs of PLHIV were not involved in any discussions on drafting of this law. Since the CBO leaders had less formal education or English language skills, they were deemed by their colleagues in the international NGOs, the government and the donor agencies, as incapable of offering expertise for framing the new law. Meanwhile, Bashir remained the undisputed leader of HIV activism, which was mainly confined to shepherding PLHIV to treatment and care programmes. Kiran also got her share of participation in high level forums and foreign trips to showcase the achievements of PLHIV in Pakistan.

The Association and the new entrant

When UNAIDS set up the Association in Pakistan with an underlying rationale of strengthening 'civil society' and 'community' participation, around 4000 people were registered with the government's ART. Many of them were also members of the CBOs but very few were willing to publically affirm their HIV status. Therefore, Bashir and Kiran were the obvious choice for President and General Secretary, while their protégés were handpicked as members of the Executive Board. Being the 'brain child' of the UNAIDS' (former) country coordinator, the Association won widespread support and some well-funded projects from the government and international donors. These projects were carried out in partnership with Bashir and Kiran's CBOs, which managed to save large investments for their own organisations in the form of overhead costs and service charges. At the same time, the participation of these two CBO leaders in high-level policy forums across government and donors and their costly international trips were also formalised as leaders of the Association representing the entire body of PLHIV in the country, not just their own factions or CBOs. However, the rise to prominence of these two formerly underprivileged individuals was challenged when Mahmood joined the Association and tried to democratise it.

Mahmood was born and brought up in the United States where he was educated as a network management engineer. He had worked in the corporate sector and lived a jovial life, as he put it, "partying all the time, alcohol, sex, sometimes cocaine, waking up at ten in the morning and not knowing whose house I was in". This was in late 1990s when he thought he would not get infected with HIV because it was "a disease of Mexicans and Black people". "That's what we saw on the telly", he said. He was diagnosed in 1999 in the US and after five turbulent years he came to Pakistan, a country of his forefathers and distant relative where he had never been before. "It was a shock to come here", he said. "Pakistan was a foreign country for me...a land of men with turbans, long beards, and missiles". These were the images he had been exposed to by the same media that had led him to believe that HIV was a disease of Mexicans and Blacks.

After arriving in Pakistan and joining his wealthy family in Lahore in 2004, Mahmood frequently flew to Bangkok for chemotherapy and radiation treatment. As his health improved, he felt the need to keep himself busy

in order to avoid slipping back into depression. He contacted a local coordinator of Bashir's CBO, who received him with great enthusiasm. Since he was educated, US-returned, and belonged to the 'upper' class, the coordinator regarded him as an asset for the CBO. In the haste of excitement, she even introduced him to UNAIDS officials without first consulting Bashir. In retrospect, Bashir told me that introducing Mahmood directly to UNAIDS was a great mistake – one for which the whole HIV sector had to pay. An even greater mistake, from his point of view, was when UNAIDS selected Mahmood for the position of the national coordinator of the Association. He had vehemently opposed this selection because he believed that he had sensed some disingenuousness about Mahmood. "He told us that he came from a rich family and that he didn't need money but wanted only to serve people", recalled Bashir, "yet, when he was offered the job, he didn't hesitate to demand a big salary". Nevertheless, Bashir's apprehensions were brushed aside by UNAIDS officials. Consequently, Mahmood, whose own health had started to fail again, was tasked with bringing back to life the Association, which had, in his words, "existed on paper only". He set out to revitalise it by changing the status quo through replacing the unelected executive board, comprising of Bashir, Kiran and their "cronies" – again his words – with a board that was to be elected by the entire body of PLHIV in the country.

Donor dependence and democratisation

Dependence on donor funding and patronage politics have been observed to have led to factionalism and infighting among people living with HIV in other contexts as well where the PLHIV sector has been observed to have remained 'heterogeneous and fragmented' with 'competitive factions scrambling for favours' (Beckmann and Bujra 2010: 1061). However, in the case of the Association in Pakistan, we can tease out how both camps espoused a sense of community of HIV positive people, the importance of numbers, the ideal of democracy, and a need to break down monopolies.

Bashir and Kiran did not reject the notion of introducing democracy in the Association, but they proposed that the executive board should be elected by a select group of CBO nominees rather than counting the opinion of every single HIV positive person in the country. "After all, who has got the numbers? It's either my CBO or Bashir's!", explained Kiran, asserting that the CBOs were legitimate representatives of the HIV positive people, and notwithstanding the fact that many had chosen not to register with either of these CBOs. However, this was not acceptable to Mahmood, who looked for ways to break the monopoly of Shining Star and Live Positive over the Association and HIV activism in general. UNAIDS, who had found a new ally in Mahmood, set up an election commission comprising of members from the government's AIDS control programmes, donor agencies, and international NGOs. Rules were introduced to bar Bashir and Kiran from contesting the elections on the pretext of avoiding a clash of interest between CBOs and the Association. Consequently, no office-bearer of a CBO was allowed to contest for the executive board of the Association. The election commission travelled to all four provincial capitals. It obtained the lists of HIV positive people from the government's ART centres to use them as voter lists, held HIV awareness seminars in local hotels, and set out ballot papers and boxes urging participants to cast their votes. Bashir and Kiran did not go to these seminars, but they also did not stop their CBO members

from attending them or casting their votes. There was hardly any voting anywhere because most of the government and UNAIDS-backed candidates were elected unopposed.

Democracy was a great ideal but it was “hard to practice” – Mahmood’s words again. There was no real voting in the elections that he had “imposed upon the Association” with the help of UNAIDS, yet the whole exercise accomplished for him the ousting of Bashir and Kiran from the Association. For Bashir, the election was nothing more than a sham; “a gathering of animals”, he told me afterwards. For Kiran too, the new executive board was a *kitchri* (a mess); “they have no funding and are pulling each others’ legs” (leg-pulling is a common expression in Pakistan meaning to bring down one’s competitors). She said allegorically about the ‘democratisation’ of the Association; “If this table was built today and you insist on having 100 people around it, also today, we do not accept that! Why? Because it takes time! And, if we start pulling each others’ legs everything will finish”. It would take time, according to her, “to break the monopoly of a few supporters of the Association” because there was no *itefaq* (unity) and *yakjehti* (agreement) in the ranks of the PLHIV ‘community’. Unless they united among themselves, she thought, their survival as a community would remain under threat from ‘agencies’ which have a vested interest in keeping them divided; “when we unite we will become a pressure group and when we become a pressure group...then....”. She stopped there. She would not be drawn about who exactly she meant by the English word ‘agencies’ and whether UNAIDS was also one of them, even though it championed ‘community building’ by bringing them together under the GIPA Principle. She laughed away the question, saying that she would rather “maintain a diplomatic silence on that”.

Shifting monopolies

Bashir and Kiran did not appreciate the logic of giving up their dominance in the field of AIDS activism merely for it to be appropriated by others, especially Mahmood, who they saw as a new but ambitious contender, a protégé of powerful interests vested outside the PLHIV ‘community’. Therefore, although they were outmanoeuvred from the Association, Bashir and Kiran did not let go of their relevance as the pioneers – never laying aside their claim on the Association in one form or the other. Even after being driven out of the Association’s executive board, they could not be dislodged from their positions of influence in the HIV sector because of they had the greatest numbers under their wings. Kiran warned against the attempts to weaken the ‘community’, which she saw in the close liaison between Mahmood and some UNAIDS officials; “as long as non-PLHIV actors have a stake in the Association, there will always remain a *jhagra* (dispute)”.

Soon after his arrival on the AIDS activism scene, Mahmood was seen as a competitor by both Bashir and Kiran. Unlike them, he was from the upper classes, rich and educated; he came from the USA and spoke fluent English. According to Bashir, he was not suitable for the Association because “he had seen nothing at the grassroots level; he was nothing, he had no reputation, and no one knew him”. Mahmood, on the other hand disliked Bashir for what he saw as advancing the interests of his own CBO at the cost of the Association’s benefit. According to him, “even the UN agencies were frustrated with Bashir”. Bashir also accused UNAIDS of not letting him ‘expose’

Mahmood. Before Mahmood arrived on the scene, Bashir had been the undisputed leader of the PLHIV sector. But now someone who Bashir thought was a ‘nobody’, a ‘nothing’, was gaining influence, securing more visits abroad and finding more favours with the English-speaking transnational elite of the donor community, and that too, by creating mistrust against him, as he saw it. Moreover, he alleged that some people among the donors who had always wanted to ‘keep everything to themselves’ had now found a collaborator to ‘hijack’ the whole sector. On the other hand, Mahmood was just as bitterly critical and dismissive of Bashir.

By introducing ‘democracy’, Mahmood had not only replaced the ‘uneducated’ executive board of the Association but by dislodging Bashir and Kiran as the President and the General Secretary and by using his influence in UNAIDS he also shifted the balance of power from the executive board to his own post of the national coordinator. Strangely enough, he justified this shift by arguing that “you have to have a board as per the bylaws but members of such boards are always different people with different ideas and backgrounds. There is too much conflict”. Therefore, if it has to become a successful organisation, according to him, “you have to entrust all powers in one person” (namely him, as the National Coordinator). This was ironic, from the man who championed breaking monopolies and bringing democracy to the Association. Soon after the elections, Mahmood left the Association to set up his own NGO for MSM. He resented that the new elected executive board had failed to live up to his expectations and that they survived merely on the “crumbs fed to them by UNAIDS”.

Instead of strengthening civil society by promising empowerment through community participation on the principle of liberal democracy, the support extended by international donors further fragmented them, stirring the uncivil element in this politics of HIV activism in Pakistan. In retrospect, Mahmood said that the idea of the Association was good, but “the time was not right” for it. For him, both Bashir and Kiran were incapable of leading HIV positive people because they were uneducated, corrupt, and could not speak English (never mind the fact that both had led their own CBOs for many years). Referring to the ‘mistake’ that UNAIDS had made by setting up the Association at a ‘wrong time’, he said; “you need to build people’s capacity first and then you give them an organisation”. Bashir and Kiran also argued that it was not yet ‘the right time’ to introduce electoral democracy in the Association; it was a ‘gathering of animals’ incapable of choosing its leaders. Thus, even though these opposing camps espoused the ideal of democracy and community building through the Association, the field of HIV activism was ridden by a multitude of contradictory claims about the right time, the right capacities and the right people for organising HIV positive people into a PLHIV community.

Conclusion

As a commitment to organising HIV positive people into a political force, to make claims upon and challenge the state, HIV activism has suggested to some observers an emergent politics over life itself, forms of biological citizenship and biosociality. However, this material from Pakistan suggests that it is inappropriate to understand HIV activism against concepts of bare life, sovereignty and exceptionalism. The HIV activists whose stories I have introduced did not enter the field from a pure concern with their biological condition – *zoe* – but from their

multitude of oppressions in a widely Islamicised society, as poor Christian, *gharailo aurat*, homosexual US-returnee and so on. They were networked into complex relations with their patrons in the transnational HIV apparatus, and with clients of their own among their family members, neighbours and social circles. As Comaroff (2007) has rightly argued, these local histories and sociologies of HIV must be taken into account; it can't be assumed that HIV activism will inevitably result in the political force of South Africa's Treatment Action Campaign, with its tradition of activism in the labour movement, anti-apartheid and health.

Following the internationally-acclaimed GIPA Principle, the PLHIV Association in Pakistan was an attempt to bring together HIV positive people into a 'community' for their empowerment. However, biosociality does not always develop in the same supportive ways as has been described. The ethnography of HIV activism in Pakistan resonates with studies from Africa (Beckmann and Bujra 2010; Boesten 2011; Marsland 2012; Prince 2012; Whyte, Whyte et al. 2013) on the conflict and competition that may systematically be associated with the NGO economy and international donor funding. These appear to have turned HIV activism into an 'extractive enclave' (Ferguson 2005; cf. Rajan 2006; Bharadwaj 2008), the end result of which has been to promote the politics of numbers in the name of democracy in order to build 'creative alliances' and 'occupy new spaces' (West 2006) in the 'exceptional' field of HIV. Moreover, amid these claims of authenticity, multiplicity of truths, contestation over numbers, diversity of actors, privileges of gender, class and religion, and the transnational assemblages of power, patronage and prestige, could the field of HIV activism in Pakistan be straight-jacketed into the model of politics in the image of a liberal democracy at all? The activists aligned themselves with the ideals of democracy, but as the ethnography shows, as they are also entangled in complex political, institutional and moral landscapes which include making moral choices and often ambivalent moral evaluations of each other's aims and situationsⁱⁱ.

In dwelling on the life histories and narratives of entry into activism of Bashir, Kiran and Mahmood, their open criticism of one another and bitter rivalries, I have shown that the field of activism is not defined only by the need for sheer survival. Whilst these pioneers and leaders entered activism in the spirit of 'making the best out of a bad situation', it became for them a field of accumulation. I suggest that this dimension has been under-explored in the existing ethnography, which has emphasised the survival strategies of HIV positive people as afflicted with a life-sapping, sometimes fatal, deeply stigmatised disease. However, a round understanding of the lives and politics of HIV activists needs to take their mercurial character on board. The 'Greater Involvement of People living with AIDS' – whether through liberal democratic principles, networks of patronage, or charismatic leadership – does not necessarily lead to strengthening the civil society. An appreciation of the moral complexity of the activists and their situation along the lines of class, religion, education, gender and longevity of HIV infection, rather the sheer survival needs of diseased bodies can lead us to gain better insight into when activism divides and when it unites; when it is a humanitarian concern and when a manifestation of biosociality heralding the possibility of some kind of political solidarity as therapeutic citizens; when it is a livelihood strategy for those who are themselves at the brink of abjection and when it is for saving others' lives or an investment in the self.

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ⁱ A pseudonym, as for all individuals and CBOs introduced in the text.

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